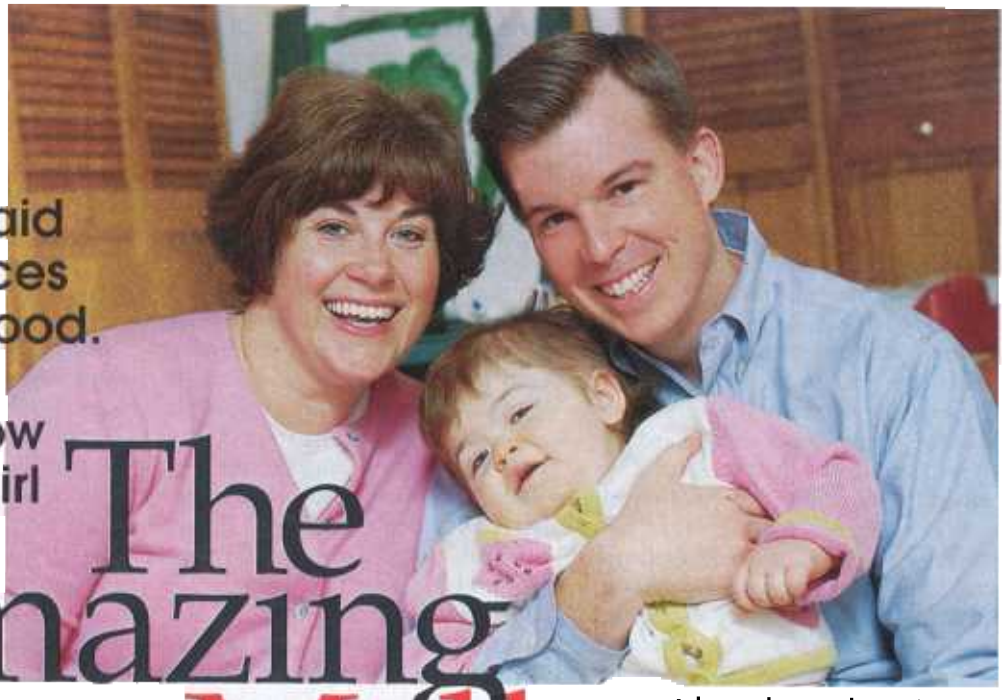
BY JENNY BIRMINGHAM

**Doctors said her chances weren't good. But they didn't know my little girl**

# The Amazing Miss Molly



John and me at home in Chicago with our little "Moo Moo," who, in just her first two years of living, has taught us a lifetime of lessons.

It was December 2000, a week before Christmas, when my husband, John, and I sat in a doctor's office and heard the words that would change our lives forever: Our 7-month-old daughter, Molly, had a rare and incurable genetic disorder called Hurler Syndrome. We were told Molly probably wouldn't live to see her 10th birthday and that her only hope for treatment was a bone marrow transplant. We were terrified.

Doctors told us that the sooner the transplant was performed, the better, so just one month after her diagnosis we brought Molly to see Joanne Kurtzberg, M.D., at Duke University Hospital in Durham, North Carolina, where she would undergo the transplant procedure. I left my job as a children's book editor to move to Durham. After the transplant, John would return to our home in Chicago to be with our son, T.J., 3½, and would visit us whenever possible.

It was the beginning of an unimaginable journey of incredible highs and lows. To keep our family and friends updated on Molly's progress, John and I set up an online diary on a Web site called CaringBridge (*www.caringbridge.com*). It was our way of keeping loved ones apprised of Molly's progress, but it also served as a source of support for us through each step of the process.

***Monday, March 12, 2001***
***11 Days to Transplant Day***
*Since we arrived in North Carolina at the end of January, Molly has had what seem like endless tests and surgeries in preparation for her transplant. Tomorrow she will be admitted to the hospital to begin the pre-transplant process, which will include heavy doses of chemotherapy and other drugs (antiseizure meds, antibiotics and meds to prevent liver disease). The chemotherapy will kill her existing bone marrow before the donor umbilical cord blood is transfused. If all goes well, the transplanted stem cells will find a home in place of her old bone marrow and grow.*

Everyone involved in Molly's case knew that the next few weeks would be an incredible challenge, most of all for Molly. The effects of the drugs she had endured for the 10 days before the transplant would start to rear their ugly heads at the same time her body was struggling to accept the new cells and start producing more of them on its own. The risk of infection was tremendous and potentially life-threatening since Molly had no immune system to fight it off.

***Friday, March 23, 2001***
***Transplant Day***
*The transplant went well. Unfortunately, Molly will be battling the many effects of treatment for the next few weeks. It is so hard to see her suffer, even though we know it's for the best. Grow cells, grow!*

In the first week after her transplant, Molly did reasonably well, all things considered. She was taking more than 12 medications and

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PHOTOGRAPHS BY LUIGI CIUFFETELLI

## THE AMAZING MISS MOLLY

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had endured continuous bouts of vomiting and diarrhea, all of which was to be expected.

Our first setback came when Molly tested positive for a respiratory virus known as RSV. The news was distressing because Molly still had no white blood cells to fight it off. She began inhalant treatments in a tent over her crib for eight hours a day. The hope was that the inhaled drug would stop the virus from causing more serious damage to her lungs.

***Friday, April 6, 2001***
***Transplant Day +13***
*Imagine being in the first car of a roller coaster. After chugging up a large hill, you're just hanging over the peak, ready to plunge down the next slope. That's how I felt this morning when I woke up to two nurses saying, "Molly grew cells!" I was so pleased (and surprised!) to know that those little buggers are dividing, despite the RSV.*

After a little more than a month, Molly found her smile again, and every time I saw her grin my heart leapt. It was wonderful to have that special part of Molly back. Unfortunately, her skin was showing effects related to the engraftment process (donor cells taking hold). She looked like she had a really bad sunburn, and her skin was extremely sensitive, so diaper changes, dressing changes, baths and lotion applications were challenging, to say the least.

Even after several weeks, Molly's lungs were still suffering the effects of RSV, and she continued to need supplementary oxygen. She would need oxygen and nebulizer inhalant treatments for quite some time, it seemed. With her lungs in this state, the idea of ever having Molly away from this "home" we had come to know began to feel a little overwhelming.

***Monday, June 4, 2001***
***Transplant Day +73***
*Molly will be discharged tomorrow! The doctors agree that Mol has her old personality back and that the transplant may have given her a little "attitude" as a bonus. She is also becoming much more cuddly again, reaching out for mom or dad, which melts our hearts. We're not out of the woods yet, but we're a step closer, that's for sure. Once we settle into our rented apartment in Durham, our days will focus on clinic trips, lots of home health issues (IV pumps, nebulizers, oxygen tanks, oral meds, blood draws), continuing therapies and, oh yes, growing hair.*

Molly had a confetti parade as we left the ward, and once we hit the road she kicked her feet in the stroller and babbled happily in the car. She was so excited to see the world again. Back at our apartment, we were met by two home health representatives. Before we even had a chance to bring in all the bags from the car, John and I were learning the ropes of respiratory equipment and IV pumps.

Although Molly was an outpatient, we made daily trips to the clinic, which gave her ample opportunity to be quite the performer. She had to be in an isolation room, which had glass doors, and all the nurses would do funny antics to get Molly going. She would throw them a smile, a few




**Molly in her inhalant tent battling RSV; the two of us all suited up for our first post-transplant journey outside the hospital room; and T.J. reading to his little sister.**

LUIGI CIUFFETELLI (right)

clicks of her tongue and a big round of applause for herself. The nurses and staff really made our long clinic days much more bearable.

***Sunday, July 1, 2001 (11 A.M.)***
***Transplant Day +100***
*I can't believe we've made it to 100 days. Due to a sinus infection this week, Molly continues to be on oxygen all the time and is vomiting every two to three hours during the night.*

On Molly's 100th day, which we thought would be a day of celebration, she took a turn for the worse. That evening she spiked a high fever with an elevated heart rate, and by 10:30 that night, when her situation hadn't improved, Dr. Kurtzberg asked us to come to the hospital. Doctors immediately put Molly on an array of antibiotics to help fight any possible infection. She was pretty spent. Her poor heart had been working so hard, and she was really nauseous, too. Although she made it through the night OK, each time her heart rate would elevate an alarm would go off, and I'd worry some more.

In the morning, preliminary results showed nothing, but her temperature was still 103 by afternoon. Finally, word came back from the lab that she did have an infection in her central line. Not good news, but it was something that could be treated with antibiotics.

In spite of this setback, Molly was soon eating more and gaining strength. She had officially cut her second tooth and was diligently working on more. One night she babbled herself to sleep, and I went to sleep with the biggest grin on my face. T.J., too, had been some of the very best medicine for Molly. He could make her laugh harder than anyone, and Molly had surpassed my expectations in every way since he arrived in Durham. One day when he heard Molly crying, T.J.

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said, "Oh, I've got to hurry. My sister needs me to cheer her up." That was his job, and he did it well.

***Wednesday, September 26, 2001***
***Transplant Day +187***
*Molly's latest tests show that she is 100 percent engrafted, meaning the donor cells have completely taken hold in her body. We have an appointment to see Dr. K. on Friday afternoon to discuss the plans for our return to Chicago this weekend. One thing is clear: Germs are Molly's worst enemy. Her immune system is working at about 25 percent capacity right now. Bringing her home, while a welcome change, is going to be a challenge.*

As we drove up our block last Sunday (eight months after we first left for Durham) every tree had a large pink bow tied around it for Miss Molly, and many of our neighbors were out on their front lawns to welcome us. The front of our house was filled with heartfelt banners and balloons, and there was one very excited little boy, T.J., jumping around the lawn. Finally, we were a family again.

***Postscript***
March 23, 2002, was the one-year anniversary of Molly's transplant, and she continues to amaze us. With eight therapy appointments a week, she is working hard to talk, walk and gain fine motor skills. Her immune system is functioning in the normal range, her enzyme level is substantial and she is developing nicely.

I am so proud of Molly and all that she has accomplished. I have watched her struggle through too many procedures and surgeries to remember, seen her suffer the side effects of chemotherapy and other drugs, helped her through blood infusions, nausea, vomiting, diarrhea, losing her hair, losing her strength, losing her voice, losing her appetite and losing her smile. But I have also seen her determination, her endurance, her resilience and her desire to overcome it all. I have seen Molly remember patty-cakes and Cheerios. I have observed her amazing physical strength and stamina and watched her try so hard to do the things she wants so badly to accomplish.

I have also stepped back and seen the unbelievable ripple of goodness Molly's life has brought about. She has inspired so many and restored people's faith in God. Her plight has given birth to new friendships while rekindling old ones. Since we launched Molly's site on CaringBridge, it has received nearly 70,000 visitors.

Molly has a very big heart and a determined little body. She has something very special to give to the world, and we're going to learn about it one day at a time. WD

## About Hurler Syndrome

Hurler Syndrome is a genetic "storage" disorder also known as mucopolysaccharidosis type I, or MPS I. It affects one out of 150,000 children in the U.S. Children with Hurler Syndrome are born without an enzyme that breaks down a particular sugar in the body. As a result, these abnormal accumulations around the heart, brain, vital organs, bones and muscles cause progressive physical and neurological damage.

The disease is usually not noticeable at birth, but symptoms begin to appear in the first two years. Physical characteristics include larger forehead, clouded corneas, clawlike hands, short stature and a curve in the lower back.

If left untreated, the life expectancy of a child with Hurler Syndrome is only five to 10 years. To date, the only approved treatment is a bone marrow or a cord blood transplant. If a child undergoes a successful transplant, many aspects of the disease are halted. However, orthopedic problems usually persist. Since 1976, approximately 150 children with Hurler Syndrome have undergone the procedure worldwide. The oldest survivor of a bone marrow transplant is in his early 20s.

## Want to know more?

*For more information on MPS I and other genetic storage disorders, visit the National MPS Society at* www.mpssociety.org.